

CARRY HOPE FORUM 2026

**Empowering Rare Voices: Advancing Equity, Innovation,
and Collaboration in Rare Disease Care**

Join us at the Carry Hope Forum: Empowering Rare Voices, where key stakeholders in Singapore's rare disease community come together to engage in meaningful discussions and interactive sessions. Part of the Carry Hope 2026 campaign organised by the Rare Disorders Society (Singapore), the forum will explore challenges, share innovative solutions, and foster collaboration – driving equitable and impactful change for individuals and families affected by rare diseases.



Event Details

Friday, 6 March 2026 | 9:00 AM - 6:00 PM
Venus Grand Ballroom, Furama RiverFront Hotel (405 Havelock Road, Singapore 169633)

Programme Outline

Registration

8:00am – 8:45am

Arrival of Guest of Honour – Dr Fereen Liew

8:45am – 9:00am

Morning Presentations

Welcome Remarks

9:00 am – 9:15 am

Mr Phua Wee Seng

Executive Director & Chief Rare Advocate, Rare Disorders Society (Singapore)



Opening Remarks

9:15 am – 9:30 am

Dr Fereen Liew

Deputy Director-General of Health (Appropriate and Value-Based Care) & Executive Director, Agency for Care Effectiveness, Ministry of Health, Singapore



Presentation of Certificate of Appreciation to Presenters

(Group Photograph)

9:30 am – 9:40 am

Patient and Caregiver Journey

9:40 am – 10:10 am

Ms Jasmine Lee

Caregiver of Sarah, Undiagnosed



Tea break and Networking

10:10 am – 10:25 am

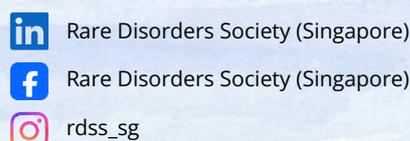
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Morning Presentations

ASEAN Rare Disease Policy Forum: Overview and pathways to better Rare Disease Care

10:25 am – 10:45 am



Datuk Dr Nor Fariza Ngah

Deputy Director-General of Health
(Research and Technical Support),
Ministry of Health, Malaysia



Dr Anh Bourcet (Nguyen)

International Director for Government
Affairs & Policy, AstraZeneca



3D AI Reads Faces to Save Lives: How technology is accelerating early and accurate diagnosis of Rare Disease

10:45 am – 11:15 am

Dr Koh Ai Ling

Consultant, Genetic Service, KK Women's
and Children's Hospital



Precision Medicine for Rare Diseases: From Bench to Bedside

11:15 am – 11:45 am

Clin Assoc Prof Tan Ee Shien

Head & Senior Consultant, Genetic
Service, KK Women's and Children's Hospital
Chief Innovation Officer, Precision
Medicine Research, Singapore (PRECISE)

PANEL DISCUSSION A:

Uniting Stakeholders to Accelerate Early Access to Rare Disease Therapies

11:45am – 12:30pm



Moderator

Mr Rajakanth R

Board Member, Rare Disorders
Society (Singapore)



Clin Assoc Prof Tan Ee Shien

Head & Senior Consultant, Genetic
Service, KK Women's and Children's
Hospital



Mr Gregory Vijayendran

Chairman, Rare Disease Fund



Asst Prof Khoo Yoong Khean

Duke-NUS Centre of Regulatory
Excellence



Mr Lim Yong Hao

Regional Patient Advocate (East Asia),
HAE International & National Contact,
HAE Singapore



Mr Samuel Koh

Director, Corporate Affairs,
AstraZeneca

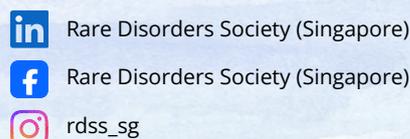
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Lunch and Networking

12:30 pm – 1:30 pm

Afternoon Presentations

Lessons from Rare Diseases: How Genetics Drives Innovation in Broader Healthcare

1:30pm – 2:00pm

Adj Assoc Prof Chin Hui-Lin

Senior Consultant, Division of Genetics
and Metabolism, Department of
Paediatrics, Khoo Teck Puat - National
University Children's Medical Institute,
National University Hospital



Harnessing Information Content: Transforming Rare Disease Screening through Data-Driven Innovation

2:00pm – 2:30pm

Dr Tudor Groza

Principal Scientist
Bioinformatics Institute / Genetics A*STAR /
KK Women's and Children's Hospital



Breaking Silos to Advance Health Outcomes & Ensuring Data Privacy and Security in Healthcare Innovation

2:30pm – 3:00pm

Ms Koh Mingshi

Director, TRUST Office, MOH Office for
Healthcare Transformation



Advancing Equity in Healthcare Through Patient-Centred Research

3:00pm – 3:30pm

Ms Ai-Ling Sim-Devadas

Deputy Director, Office of Patient Engagement
Lee Kong Chian School of Medicine,
Nanyang Technological University



Tea Break and Networking

3:30pm – 4:00pm

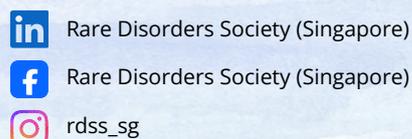
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PANEL DISCUSSION B:

Balancing Privacy and Progress: Ethical Use of Health Data in Research and Innovation

4:00pm – 4:45pm



Moderator

Ms Ai-Ling Sim-Devadas

*Deputy Director, Office of Patient Engagement
Lee Kong Chian School of Medicine,
Nanyang Technological University*



Ms Koh Mingshi

*Director, TRUST Office, MOH Office for
Healthcare Transformation*



Dr Seow Shih Wee

*Senior Director & Chief of Staff, Precision
Medicine Research, Singapore (PRECISE)*



Dr Melissa Chan

*Vice Chairperson,
Pulmonary Hypertension Singapore*



Ms Erin Koek

*Senior Country Manager,
India, Pakistan & Southeast Asia,
BioMarin Pharmaceutical*



**Innovative Regulatory
Approaches to Accelerate Access
to Rare Disease Therapies**

4:45pm – 5:15pm

Asst Prof Khoo Yoong Khean

*Duke-NUS Centre of Regulatory
Excellence*



Closing Remarks

5:15pm – 5:30pm

Mr Phua Wee Seng

*Executive Director & Chief Rare Advocate,
Rare Disorders Society (Singapore)*

Networking

5:45pm – 6:00pm

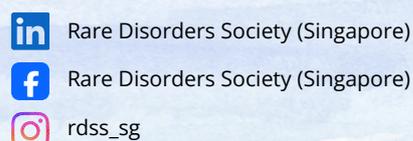
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